

Providing person-centred support for people living with dementia at home during the COVID-19 crisis

This information sheet has been developed by the Association for Dementia Studies at the University of Worcester (www.worc.ac.uk/dementia) to help formal caregivers of people living with dementia at home during this difficult time. It is best practice at the time of writing and general advice only, the latest national sector guidance should be followed.

The transition to receiving care at home or any change to normal routine can be very stressful for a person living with dementia at the best of times; even more so during this crisis. This guidance aims to help you reduce this stress and be person-centred during this challenging time. Every person is different and so the way they experience this crisis and the help they need will also be different. It is also a difficult time for care workers, so this guidance should reassure you that you're providing good support, even though circumstances are very unusual and demanding.

It is important to remember throughout that the Mental Capacity Act still applies to the way we work with people living with dementia. When someone lacks the capacity to make an informed decision about how to live day-to-day during this crisis, they have the right to have good decisions made on their behalf: decisions that aim to achieve their best interests in the least restrictive way possible. This will mean **balancing the need for social distancing, isolation and infection control with any negative impact or distress those measures may cause a person** who cannot understand the current situation. Whilst social distancing/infection control are in people's best interests, there are different ways to achieve these and you should aim for the one that physically restricts the person the least and emotionally supports their well-being the most. This is a careful, individual and changeable judgement call.

Strategies to help the person understand the COVID-19 situation

When working with a person living with dementia it can be easy to assume that they cannot understand what is happening, but people often take-in more than we think. Finding a few simple ways to explain the current situation can be very helpful. However, if the individual appears to be distressed by any of these, do not pursue them.

- Whenever possible try to ensure the same caregivers continue to visit in the usual routine for the person (unless extra calls need to happen). This will help provide reassurance and familiarity in an uncertain time.
- Provide a simple written explanation of the situation. It could be read with the person and then left for them to read again later in their own time.



- Display a simple poster in key places for the person (e.g. front door, or above the kitchen/bathroom sink).
- Use a simple explanation for the situation that can be consistently used by everyone (e.g. *“there is a very nasty bug around at the moment and so we have to stay inside to keep ourselves safe”*). This will help some people to remember and also ensure that worker’s worries are not inadvertently passed onto the individual.
- Remember that seeing someone in full PPE can be frightening and so reassurance will need to be given at every interaction, even when you’re used to the situation. Having photographs of you and others without PPE can be useful for this.

Useful links and resources

- An easy-read guide to social distancing: [Easy Read - 'Keeping away from other people'](#)
- Dementia: The Montessori Way provides a [simple COVID-19 poster and booklet](#)

Strategies to ensure the home is well-equipped to meet a person’s needs during isolation

As much as possible should be done to ensure that an individual’s home is well-equipped during the isolation period, especially as there may be a significant reduction in familiar visitors and outside support. Any items brought in from outside the home will need to be quarantined/disinfected prior to being used, so forward planning is important.



- As a caregiver, make sure you know as much information about the person as possible. This is helped by keeping the same caregiver/s as usual. If the usual person cannot visit, make sure that key information is shared before the visit.
- Have significant items easily accessible in the person’s home. These might include photographs, diary, important objects, handbag etc.
- Consider whether using technology could help with safety at this time (e.g. fall alarms, door sensors etc.)
- Encourage family members/significant people to write a letter, record a film or audio message reassuring the individual that they are safe, that family/friends are in touch, and that there are special rules everyone has to follow at the moment. This can be used regularly with the person.
- Make sure that the person’s TV, radio, CD player and/or digital music player is working.
- Plan in advance for activities that may keep the person occupied. This can change as you get to know what works or doesn’t work, but don’t let boredom set in!

Useful links and resources

- The ["this is me" document](#) is a simple way to gather information to get to know the person if you don’t know them well

Strategies to occupy the person at home during isolation

The key to encouraging a person to stay at home is to make that space interesting and reassuring. A lot of distress and seeking-out behaviour stems from boredom.



- Maintain as much of the same routine as possible for the person living with dementia and support them to do as many of the same familiar, daily activities as possible. For example, building a schedule around regular TV or radio programmes shows can help to maintain a sense of normalcy.
- Create a daily plan based on the person's favourite music, TV and hobbies. This should focus on providing engaging activity *throughout* the day rather than at fixed times, and be pitched to the abilities of the individuals (e.g. folding laundry, sorting items in a rummage box, tidying a drawer, looking at photos, painting a picture, reading or watching a specific DVD).
- Ask families or local volunteer groups to make up activity boxes/packs for the individual. These should contain anything that might hold the person's interest. Make sure the items are suitable and disinfected if needs be before being brought into their home.
- Whenever a caregiver interacts with the person they should ensure they're engaged in an activity before they leave (e.g. "We have some socks here that need sorting, could you help by pairing them up for me?"). Initiation of an activity, even when materials are in reach, can be difficult for many people living with dementia.
- Music is known to be very powerful for people living with dementia. Unless it distresses the person or conflicts with an alternative activity, ensure the person has music playing that they enjoy. Pay special attention to music that comforts and relaxes the person; you could discuss and play favourite CD's the person has in their home.
- Consider using simulated presence: This is an audio or film recording from a significant person that reassures the individual that they are safe, and that family and friends have not forgotten them. You could get creative with this: maybe a young family member who needs to practice their reading could be filmed telling a story and shared with the person?
- If they can, try to help the individual stay physically active. You can access exercise videos that are being posted online. This could be a part of the new daily routine.

Useful links and resources

- The [National Activity Providers Association](#) has made their resources free including this [Guide to activities during social distancing](#)
- [Playlists for Life is](#) a great website for music in dementia, including some covid-19 resources
- [Active Minds](#) sell activity kits for people of all abilities and designed with infection control in mind
- A guide to: [online resources for activities for older people](#)
- Many exercise classes have moved online, such as this 'dementia friendly' [seated exercise class](#) or these ones from [Leominster Meeting Centre](#) Facebook page and on [You Tube](#)

Using the physical environment to encourage isolation

The physical environment is a useful tool for helping to orient an individual and to encourage or discourage certain activity. However, it is very important to make sure that measures aren't overly-restrictive as this can cause greater frustration and activity from the person, increasing risk.

- Make sure the person can see out of their windows and that the view is not obstructed by large items on windowsills or TV screens.
- Maximise connection to nature/the outside by making sure curtains are not blocking natural light. You could make a simple [birdfeeder](#) for them to watch outside the window
- If you are worried about the person leaving their house because they might forget about social-distancing rules, place a simple poster on the front door, or near where they keep their keys. If there is a safe outside space they can go to, the poster could direct them there.
- Make sure the person can see their favourite items from where they spend most of their time (e.g. bed or chair).
- If the individual would like one, make sure that there is an easy-to-read clock and calendar in their home to support orientation. Including some guidance about staying at home with these items could be a helpful reminder for the person.
- Make sure snacks and drinks (if safe for the person) are available to easily access throughout the day. If a person is unlikely to check in cupboards or struggles to make a drink or snack themselves, this would mean making sure that snacks and drinks are visible to them without searching. It will also be important to make sure they are well-stocked with their favourite foods and drinks. These measures will reduce the likelihood that the person will leave the house to buy food/drink.



Strategies to meet people's need for human contact

It is very important to remember that contact with others is a basic human need and so people living with dementia will naturally seek it out. Social isolation may be in a person's best interests right now, but that means we need to try and meet the need for human contact in other ways. The better you achieve this, the less likely the person is to try and seek out that contact or show their frustration through their behaviour. Keith Oliver, a well-known speaker who lives with dementia himself has encouraged people to think in terms of **physical** distancing rather than 'social distancing', because social contact is so important for people's well-being.



- Try to facilitate safe time outside of the house several times a day, especially if this is part of the person's usual routine. This could be as simple as sitting in the garden for lunch or a trip down the street looking at neighbour's gardens. Physical exercise will help relax a person and improve sleep.

- Interact with the individual as much as possible when you are visiting and talk about familiar things rather than focussing on getting tasks done.
- Facilitate regular contact with families and friends via writing letters, telephone and online calls. These people may need reminding that their contact is really helpful at this time.
- Think about whether there are any weekly newsletters you can access for the individual with activities in such as bird bingo, sunflower seed competition, word searches or poems. Many community organisations have created online and postal resources during this time.
- See whether neighbours or local community groups could help to provide some contact. Many new groups have sprung up at this time and have organised innovative things such as putting children's drawings in the window, encouraging children to wave as they go on their daily exercise, regular check-in chats on the phone or through a window etc.
- Consider using technology to help the individual connect with others. Platforms such as [ZOOM](#) and [WhatsApp](#) can facilitate this and can be downloaded on iPads, smartphones or computers. Many people living with dementia have managed to learn how to engage online and meet with other people in this way during the crisis and have found it very helpful
- Facilitate participation in online groups such as singing for the brain, seated exercise etc. there are some links below and you'll be able to find others.

Useful links and resources

- Several dementia singing groups have been made available online:
 - [Blue Skies Singing Group Online Session 1](#)
 - [Singing for the brain session - Spring](#)
 - [Singing for the Brain - session 2](#)
 - [Singing for the Brain - session 3](#)

Strategies to encourage a person to follow additional infection control measures

- Always explain what is happening and why each time you interact. For example, explaining why you are having to wear a mask or visor can be reassuring.
- Have simple, clear notes/posters in the kitchen and bathroom explaining why it's important to wash your hands more regularly.
- Do the activity alongside the person (e.g. wash your hands as well). Copying an action can be easier to follow than verbal instructions.
- Try to link into knowledge of the person to help e.g. "When your children were little did you have to make sure their hands were clean before meals?"
- Use music, singing and general chat to make sure these interactions are enjoyable. This is more important than ever during this time.
- If a person likes to be busy, provide them with anti-bacterial wipes and encourage them to clean (e.g. kitchen surfaces). This may be particularly useful for people who need to be very active to help ease frustration.



Remember: These are tough times, but they will end. Why not keep a list of all the things you and the person would like to do when physical distancing/isolation is no longer required?